# Program Overview



### HISTORY OF THE ORGANIZATION



- ► The Sickle Cell Association of Texas Marc Thomas Foundation started in 1997 by a husband and wife who wanted to advocate for families suffering from sickle cell disease
- ▶ Pastor Marc Thomas suffered from sickle cell disease, pulmonary hypertension, congestive heart failure and wore oxygen 24 hours a day
- ▶ He passed away from sickle cell disease at the age of 46 by his wife and daughter continues his legacy and mission

## Sickle Cell Trait and Sickle Cell Disease

# Normal red blood cell (RBC) Normal red blood cell section Normal red blood cell section Normal sickle red blood cell section Abnormal sickle red blood cell section Sickle cells blocking blood flow Sickle cells blocking blood flow Sickle shape

- Sickle Cell Disease is a genetic disorder and all newborns are tested for it in Texas
- It affects the red blood cells
- It causes severe pain, jaundice, blindness, organ damage and early death
- There is no cure
- Many with sickle cell trait are unaware they are carriers

### SERVICES AND PROGRAMMING

- We serve hundreds of clients thanks to City of Austin funding:
- 1. FREE sickle cell trait testing, 1 in 12 African Americans have sickle cell trait- there is an estimated 10,894 individuals in Travis County including Hispanics, Caucasians, Asians and others
- 2. Certified Case Management, Referrals, SSI/SSDI Assistance, Housing, Transportation assistance and more
- 3. Counseling, Transition Services, Care Coordination, Medical Home Placement, Scholarship Program, Support & Limited Financial Assistance, Outreach, Education, Camp opportunities, SOS Support Group Meetings

# **ACCOMPLISHMENTS**



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Lenora Johnson, DrPH, MPH Director the National Heart, Lung, and Blood, Institute (NHLBI)



Dr. Cara James, Director of the Office of Minority Health at the Centers for Medicare and Medicaid Services (CMS), and Gary H. Gibbons, M.D., Director of the National Heart, Lung, and Blood Institute (NHLBI) at the National Institutes of Health (NIH)



Texas Sickle Cell Advisory Committee

# **ACCOMPLISHMENTS**



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The Science

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Today's Faces of Sickle Cell Disease

### Linda Thomas Wade

September 04, 2018

Health care educator, patient advocate, minister, president and co-founder of the Sickle Cell Association of Texas Marc Thomas Foundation

# FACES OF SOME OF OUR FAMILIES

